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Intersex and Families: Supporting Family Members With Intersex Variations

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Intersex and Families: Supporting Family Members With Intersex Variations

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Introduction

People with intersex variations are born with atypical sex characteristics, whether chromosomal, hormonal, or anatomical (Jones et al., 2016). Some intersex variations can have hereditary links – for example, Turner syndrome (TS) and androgen insensitivities (Ahmed & Fadl-Elmula, 2016; Dong, Yi, Yao, Yang, & Hu, 2016; Kim, Sock, Buchberger, Just, & Denzer, 2015;). Therefore, people with intersex variations may or may not have family members who share some or all of the features of their variations. Researchers have argued that there are inadequate studies of the effect of intersex variations on families and on the general experiences of family of people with intersex variations (Ahmed & Fadl-Elmula, 2016; Dong et al., 2016; Grimbly, Caluseriu, Metcalfe, Jetha, & Rosolowsky, 2016; Kim et al., 2015;). This article considers the complex dynamics of family relationships for people with intersex variations, filling a significant gap in the existing literature on family strengths studies of intersex issues. It specifically aims to explore the effect an intersex diagnosis may have on individuals and their families, drawing on Australian data reported only broadly elsewhere in ways that considered people with intersex variations as individuals (Jones et al., 2016), without considering the participants as family members both contributing to, and affected by, family dynamics. It explores the hypothesis that family relationships are strained by the disordering of intersex variations, which is viewed as problematic. First, it supplies a brief review of the international literature on family dynamics for people with intersex variations. Second, the article draws on the largest sociological survey of people with intersex variations in the global South and on interviews with people in their family and Australian service provision networks. It examines the previously unexplored findings on the hereditary links related to intersex variations and issues surrounding interfamily disclosure of intersex variations, family-based support, and the pressure experienced by people with intersex variations on themes of health care and information dissemination, and how people with intersex variations feel service providers and family members can exacerbate or mediate these issues. Finally, the article calls for future research in the field of intersex studies and potential programs supporting families with intersex variations.

Intersex and Family Research

Aside from broad calls to include intersex themes in education in a social justice lens (Koyama & Weasel, 2002; Savage & Harley, 2009), there is a lack of research on the social relations of people with intersex variations generally. Most research is from Europe, North America, and Canada and

uses a medical frame; specifically, the studies mainly understood intersex variations as “disorders of sex development” (DSDs), took place in clinics, and focused on assessing and fixing atypical sex traits as health “problems.” Key research considered the biological makeup of participants, their physical presentations, and their buccal smears or chromosomal compositions (Balen, 2007; de la Chapelle & Hortling, 1962; Lux et al., 2009; Turner, Greenblatt, & Dominguez, 1963), and some focused on genetic links in families (Ahmed & Fadl-Elmula, 2016; Dong et al., 2016; Kim et al., 2015). The largest medical study of people with intersex variations was a German, Austrian, and Swiss clinical evaluation of the treatment satisfaction of 439 children, adolescents, and adults “with DSD” and their parents (Lux et al., 2009). It comprised a collection of DSD-specific psychosocial medical data gathered by attending physicians. Over 80% of participants had been subjected to surgeries because of their intersex diagnoses, and many younger participants who had undergone interventions with their family’s guidance (e.g., coercion or urging) had experienced significant disturbances in family life. Problematically, the research group nevertheless did not conclude that there were risks to family dynamics related to early interventions for people with intersex variations. A Swiss study considered why parents generally avoid postponing surgery until their child is old enough to provide consent (Streuli, Vayena, Cavicchia-Balmer, & Huber, 2013). The study used 89 medical students positioned as potential parents and surveyed their consideration of whether they would subject their imagined child to surgery during infancy. The level of medicalization of the diagnosis itself (whether the diagnosis was pathologized) affected parents’ decision making, including that interventions were more frequently approved for pathologized diagnoses. Davis (2015a), a sociologist, interviewed 36 adults with intersex traits and found that although some rejected the pathologizing medical term “DSD,” their families sometimes used such medical terms nonetheless. Overall, the research literature highlighted a need for greater investigation into the familial links to intersex variations and into the general experiences of family of people with intersex variations (Ahmed & Fadl-Elmula, 2016; Dong et al., 2016; Grimbly et al., 2016; Kim et al., 2015; Lux et al., 2009; Streuli et al., 2013). There was a particular lack of sociological work considering the perspectives of people with intersex variations on these issues (Davis, 2015b).

Critical and Postmodern Intersex Studies

Critical approaches to intersex studies privilege whole-scale reforms to thinking on intersex variations and human bodies in general (Liao &

Simmonds, 2014). This critical frame sees people with intersex variations as a marginalized group whose rights to non-discriminatory treatment and empowered selfhood are under threat from society's key institutions. The critical approach posits that intersex bodies should be accepted, valued, and celebrated and that liberal orthodoxy within both medicine and activism (focused on providing options for changing intersex bodies) should be challenged. Critical approaches advocate for a focus on empowering marginalized intersex groups to determine if any such intervention options are even necessary, and combating systemic bias against intersex bodies and people (Davis, 2015a; Liao & Simmonds, 2014). Grabham (2007) calls for a holistic inquiry into intersex citizenship and the effect of assumptions about the corporeal (physical bodies) on key social structures – including the family. Postmodernists/poststructuralists have alternately viewed sex as one category with many potential outcomes, a varied and complex spectrum ranging between two extremes (female and male) or as involving many combinations or possible expressions that are then socially interpreted into biological categories, sometimes falsely (Fausto-Sterling, 2012). Morland (2006) argued that none of the features of the postmodernist approach unequivocally support the reformist agenda of intersex activists around issues of medical health and social inclusion (intersex activists called for the treatment of intersex people to be completely reformed). However, Morland claims that the very ambivalence of postmodernism suits the diversity of views held by people with intersex variations. Research in this perspective can thus explore how useful different understandings of intersex can be (Morland, 2006). The study that this article reports on aimed to explore the family experiences of people with intersex variations and their health needs from their own perspectives, privileging their empowerment by putting forth their own voices and views. It was organized around a combination of both critical and postmodern framings, particularly casting key intersex community representatives as advisors on the research design to consider their insights. The project was also framed around the perspective that all constructions of people with intersex variations are socially determined (rather than innately “true”). Therefore, the project cast all constructions of the group as affected by a range of social institutions (e.g., including views of the families and medical institutions they were exposed to). The influences of these social institutions on the participants were therefore carefully considered.

Study Design and Methods

Australian Context

The stigma surrounding people with intersex variations can hamper critical social research (Davis, 2015b); however, this stigma is now being challenged. The United Nations (2012) asserted the protection of all people against discrimination on the basis of intersex status in international human rights law. The Council of Europe (Agius, 2015) also outlined eight recommendations to member states for their treatment of people with intersex variations, including recognizing that people with intersex variations have the right not to undergo medically unnecessary “normalizing” treatment, supplying counseling, and conducting research into the needs of people with intersex variations in different settings. Australia’s national Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 made discrimination on the basis of intersex status unlawful (Australian Parliament, 2013). Australia was therefore seen as an appropriate case study for this inquiry into family because it was the first of only three countries in the world to develop direct legislative protection for the group, allowing these individuals to discuss their experiences in the study within the context of a clearer legal framework. Australia also hosts highly active and accessible networks of people with intersex variations and related stakeholders in family and health services, who have been instrumental in facilitating research inquiries.¹

Survey Instrument

An anonymous online survey was used to collect the data reported in this paper. The 10-page questionnaire contained 61 questions, including both forced-choice (quantitative) and open-ended (qualitative) questions developed by the researcher and advised on for sensitivity of wording by the reference group of representatives from organizations for working people with intersex variations. It was hosted by Survey Monkey and had a URL that included the term “ausvariations.” Questions on family included occurrences of variations within participants’ families, family discussions of intersex issues, family support levels around intersex variations, and family information sharing. Questions also considered the family’s contribution to the participants’ gender rearing and behavior, surgical and hormonal medical interventions, and feelings about having intersex variations. Participants were also asked about their views on key parenting

¹ The researcher thanks the reference group advising on the sensitivity of language for collection of the original data, including representatives from the Androgen Insensitivity Syndrome Support Group Australia (AISSGA); Organisation Intersex International (OII), and National LGBTI Health Network.

debates about rearing a child with intersex variations. The questionnaire asked participants for their level of agreement with statements such as these: “Children should have genitals that precisely match the sex they are reared as.” “Adequate choices and information were given to my parents about my congenital sex variation when it was first diagnosed.” Answers were given on a five-point Likert scale (“Strongly Agree,” “Agree,” “Neutral/Unsure,” “Disagree” or “Strongly Disagree”). Completion times for the survey varied greatly (between 15 minutes and 2 hours).

Ethical Considerations

Ethical approval for this project was obtained from the University of New England Human Research Ethics Committee. All participants had the right not to answer any question. Younger participants (aged 16-17 years) were not required to seek parental approval for their participation in the study, in recognition of anecdotal reports that they might experience discrimination and abuse in the home. The design of the study considered these participants’ vulnerability, supplying links to related help lines and support groups and using random author-selected pseudonyms based only on the self-reported gender of participants.

Sampling and Recruitment

The target group comprised people with intersex variations aged 16 and older. Participants needed to self-select to be part of the research; however, only data from participants with the medically recognized intersex variations listed in the survey were included in the analysis. These variations included polycystic ovary syndrome (PCOS)–related hyperandrogenism (defined as a medically recognized intersex variation in Huang, Brennan, & Azziz, 2010). The survey was opened in May 2015 and closed June 2015, after two months. Various media were used to promote the project: intersex groups, networks, and services; various mainstream and alternative media (print, electronic, and radio); intersex social networking pages; websites; e-lists; e-mails; individual advocates; endocrinologists; urologists; medical practitioners; ABC Radio; and word of mouth among people with intersex variations.²

² Some organisations who promoted the survey included AISSGA, The Australian Safe Schools Coalition, Australian X & Y Spectrum Support, The Australian and New Zealand Gender Support Group, The Freedom Centre, Genderqueer Australia, Genetic Network of Victoria, GSMA@Queerspace, Intersex United, Klinefelter’s Syndrome Australia and SA, Laura’s Playground, Le Syndrome De Turner, The National LGBTI Health Alliance, OII Australia, Polycystic Ovarian Syndrome Support Group, PCOS Australia, Reddit Intersex, SA Equal Opportunity Commission, ShineSA, Sistergirls & Brotherboys

Data Analysis

Final data were downloaded from the Survey Monkey site and then transposed into quantitative computer programs (SPSS v10, Excel). The data were screened and cleaned, and over 50 participant surveys that did not fit the target group were excluded. Three main groups of participants were excluded: (1) those who had done the survey by mistake or out of curiosity, (2) those who had contributed only (anti-intersex) abuse, and (3) those who otherwise gave responses inconsistent with having genuine intersex variations. Finally, there was a group of 16 excluded participants who understood their transgender status as a kind of intersex variation, although they did not have any intersex variations. These participants were excluded because their experiences were not consistent with having a variation (their experiences of their physical body and their attitudes and experiences around hormonal and surgical interventions were very different from those of the rest of the group, and they simply could not complete the survey after a few pages). However, participants who were transgender and *did* have intersex variations were included. Descriptive and comparative statistical analyses were undertaken. Grounded thematic analyses were also performed on participants' written short-answer responses to questions related to family dynamics and family issues. Although chi-square comparative tests were conducted to explore any differences in family-related data by age, sex, or location (Australian vs. international location groups) reported here, this information is not reported. Importantly, this study generated a *largely descriptive account* of family issues to generate some base data on the topic in the first instance from which perspectives for future intersex studies on families could later be formed.

Findings

Demographics

Overall, 272 people with intersex variations aged 16 to 87 years completed the survey. All Australian states were proportionately represented in the study,³ and 4% of these participants were Aboriginal or

Australia, Susan's Place, Turner's Syndrome Girls (XOers), Two Spirits QAHC, XXY/Klinefelter Syndrome Society, YGender, and others.

³ Of the Australian participants, most came from the three most populated states: New South Wales (32%), Victoria (21%), and Queensland (18%). There were also participants

Torres Strait Islander. One-fifth of the participants currently lived internationally – mainly in the United States and United Kingdom.⁴ In total, 74% of the group had no religious affiliation, and 27% had disabilities (e.g., anosmia, motor skill development delay, movement impairments, osteoporosis-related bone density loss, scoliosis, etc).⁵ The participants were living mostly in relatively stable situations with their loved ones: 34% with their partner, 23% with their parents, and 17% with friends; only 17% lived alone – figures comparable with those of transgender people (Jones, del Pozo de Bolger, Dunne, Lykins, & Hawkes, 2015). Approximately 6% reported that they were in a more precarious context or homeless, couch surfing, or living on the street – a percentage similar to the high incidence of homeless gender-questioning youth in other studies (Jones & Hillier, 2013). Also, 2% were living at college, and a further 6% described other living arrangements.

Of the participants, 52% were allocated a female sex at birth, and the same proportion use that marker now; 41% were allocated a male sex at birth, yet only 23% use that marker now. The decrease in the use of male sex markers since birth allocation was explained by an increase in the identification of alternative sex options later in life (X, unsure, another option). However, only 8% of participants identified as transgender. Changes in sex marker use mainly related to individuals' fundamental disagreement with medical practitioners' assessment of their physical sex characteristics (not their gender identity). Over a third of the group used multiple sexuality labels: 48% used "heterosexual," 22% "bisexual," 18% "gay" or "lesbian," 15% "queer," 11% "questioning," 10% "pansexual," 10% "asexual," 10% "prefer no label," and 4% "another label" – most commonly "fluid." Participants were asked to select any variations that they were born with from an alphabetical list of over 30 options ranging from 5-alpha reductase deficiency (5-ARD) to XY-TS, including "unknown" and "another option." On average, the 272 participants reported having two of the

from Western Australia (6%), South Australia (10%), Tasmania (2%), the Australian Capital Territory (5%), and the Northern Territory (4%).

⁴ Most commonly, internationally based participants came from the United States (31 people), England (7), Canada (3), and New Zealand (2). There were also individual participants based in a range of nations, including Austria, China, France, Germany, Greece, Italy, the Maldives, Scotland, and Sweden.

⁵ The type of intersex variation that participants had did affect the disabilities some experienced, although because of the small numbers for each variation, comparative statistical tests cannot be reasonably applied, and other factors applied (including, for some, the interventions they experienced). For example, all (and only) participants with Kallmann syndrome had anosmia, and several participants with Turner syndrome had experienced joint (knee/elbow) problems and heart problems.

options listed (Table 1). Overall, more participants preferred to use the word “intersex” to discuss their own variations (60% used **one or more** terms related to “intersex”: 48% used “intersex,” 20% “intersex variation,” “18% intersex condition”) than other terms (25% “diagnosis,” 17% “my chromosomes,” 7% “difference of sex development,” and 3% “disorder of sex development”).

Table 1. Intersex Variations of the Study Participants ($n=272$)

Answer Choices	Responses, No.
5-Alpha-reductase deficiency (5-ARD)	2
17-Beta-hydroxysteroid dehydrogenase deficiency	3
Aphallia	1
Bladder exstrophy	4
Clitoromegaly (large clitoris)	14
Classic congenital adrenal hyperplasia (classic CAH)	10
Complete androgen insensitivity syndrome (CAIS)	20
Cryptorchidism (undescended testicle/s)	17
de la Chapelle syndrome (XX male syndrome)	4
Epispadias	1
Fraser syndrome	2
Gonadal dysgenesis (partial or complete)	8
Hypospadias	12
Jacob/XYY syndrome	2
Kallmann syndrome	4
Klinefelter syndrome	25
Late-onset congenital adrenal hyperplasia (late-onset CAH)	2
Leydig cell hypoplasia	1
Micropenis	21
Mosaicism involving “sex” chromosomes	7
Mayer-Rokitansky-Küster-Hauser syndrome (müllerian agenesis, vaginal agenesis, congenital absence of vagina)	6
Müllerian (duct) aplasia	1
Ovotestis (formerly “true hermaphroditism”)	16
Partial androgen insensitivity syndrome (PAIS)	24
Persistent müllerian duct syndrome	0

Polycystic ovary syndrome (PCOS)–related hyperandrogenism	38
Progestin-induced virilization	1
Swyer syndrome	4
Turner syndrome (TS, one X chromosome)	10
Triple-X syndrome (XXX)	1
47,XXY syndrome	31
XY/XO mosaics	8
XY-Turner syndrome (XY-TS)	2
Unknown	22
Another variation	29

Families' Initial Discussions of Intersex Variations

The survey asked the participants at what age they had started to learn of their intersex variations. Most (64%) had learned of their variation for the first time before the age of 18 years and a third as adults; a small number were still unsure of the full details of their variation when they completed the survey (Figure 1).

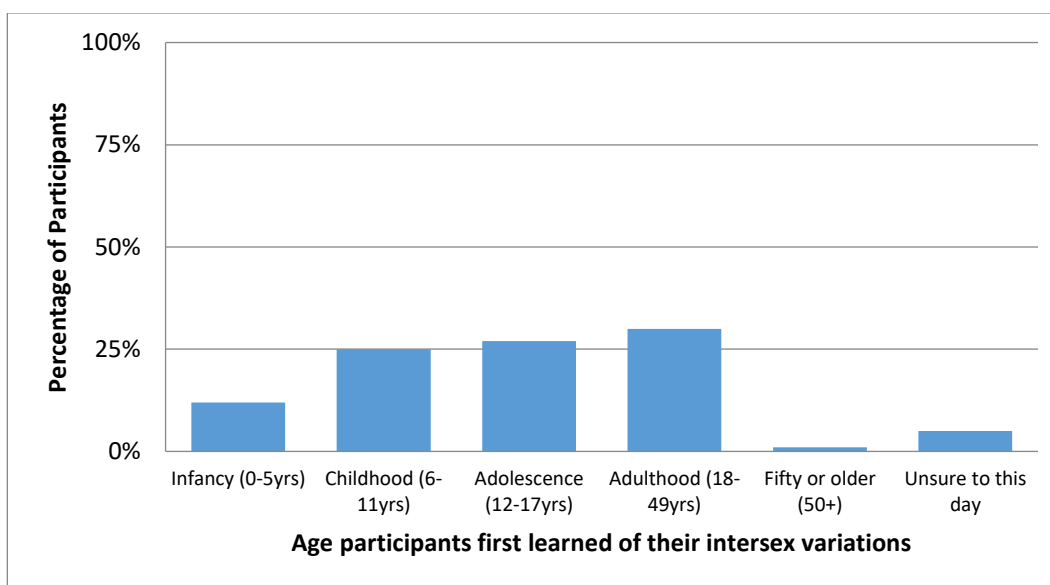


Figure 1. Age at which participants first learned of their intersex variations (n=212).

The survey then asked participants to share how they found out (from whom, why, and how) in a short-answer response. In the largest proportion of the responses (87 responses), a participant had been being told about an intersex variation by one or both parents, most commonly just the mother (39 responses) or both parents (37 responses), and less commonly just the father (11 responses) or another guardian. The discussions usually took place at home or in the car, often in relation to a doctor or hospital appointment (before or after, or because the participant had asked a question about the appointments). Typically, information for the participant was inadequate, with little follow-up. Briony (a female with TS /one X chromosome) asked her mother why she had to keep going to hospital and doctors' appointments when nobody else she knew did when she was a child. "I was very surprised to get a real answer," she recalled:

I was actually just having a tantrum as I really did just think it was a leg problem, not an XO problem, hard to get your head around that as a kid and I wish it did not come up during a fight like that.

Louise, a woman with complete androgen insensitivity syndrome (CAIS), was told by her parents after she had attended a sex education lesson during primary school, years after they had found out. They had received her diagnosis from Louise's weeping doctor without Louise present, after he had performed abdominal surgery on her at age 7. Her parents had also wept. Louise remembered, "They told me I had 'testicular feminization' but were unable to explain the condition beyond asserting that I had no uterus, would not menstruate, and could not have children." Apart from taking her to the family general practitioner to commence hormone replacement therapy (HRT) at the start of high school, her parents never provided Louise with any further information or discussed the condition with her again. "To this day, my parents don't understand the condition," she reflected. Left to her own devices, Louise stumbled across outdated information about "hermaphrodites" in her school biology text book and began to suspect that there was much more to her own condition than what she knew about it. Finally gaining Internet access at her university, by her early to middle twenties she had accumulated enough information online to realize the potential long-term health consequences of her HRT. She insisted that her general practitioner refer her for bone density testing, and endocrinologic and gynecologic reviews. "Despite evidence of osteopenia, no education or adjustment to routine HRT was provided," she stated. "In my early thirties I eventually

commenced consulting a holistic general practitioner, who was willing to consider bio-identical hormone therapy and additional nutrition supplements, which helped remediate osteopenia.”

In the second largest proportion of responses (77 responses), a participant was told about the intersex variation by a doctor, endocrinologist, gastroenterologist, urologist, or gynecologist (or some combination of these medical practitioners). The discussions usually occurred at the doctor’s office or hospital and often occurred in relation to a particular test result that was being awaited or had arrived, or a procedure that the participant was about to undergo. Typically, the experiences involved embarrassment for the participant or a negative response by the doctor, such as making blanket pre-emptive claims about fertility or the treatments the patient “should” undergo rather than affirming the patient’s diversity or diverse options. For example, Olivia (intersex woman with CAIS) had no menstrual cycle by the middle of her teenage years and went to her doctor to undergo tests to explore why. “My doctor told me that lab work, x-rays, and an ultrasound determined I had CAIS,” she recounted. “The doctor said I could not have kids and handed me a booklet to read.”

Mary (a woman with the intersex variation non-classic congenital adrenal hyperplasia [CAH]), had no period in her late teenage years, “crazy acne,” and hair growth on her body when her mother became concerned about her hormone levels and took her to the doctor’s office. The doctor did a physical examination of Mary and obtained some x-ray studies and blood samples. Mary found the process uncomfortable, explaining, “I also had to give them my pee, all pretty embarrassing, as if the exam was not enough.” The doctors found that she did not have a full uterus and “had all these hormone level symptoms of some kind of lower-level congenital adrenal hyperplasia.”

Francis, a transgender woman with the intersex variation partial androgen insensitivity syndrome (PAIS), had “mixed attributes” while growing up, which led to her being read “unpredictably as male or female.” Although her parents had raised her as a boy, when a doctor suggest she had PAIS and discussed this with her parents, they finally disclosed “childhood medical details that confirmed this” that they had previously withheld. The details included that they had been advised by doctors to give her testosterone as a teen but did not comply. This was a decision Francis was grateful for, although she wished her parents had been more forthcoming about her variation so that she had not had to find out about her PAIS from a doctor years after a difficult and confusing adolescence.

A third and slightly less common theme in other participants' responses to this question involved exposure to documentation that revealed key information, either by accident or on purpose. Examples from this group, such as Bailey (intersex nonbinary individual with Klinefelter syndrome), looked at their birth certificates as children and saw that they had been recorded as "XXY." They wanted to know what it meant, so they started looking into a book they had been given about where babies come from, with the basics of genetics and reproduction, saying that because so little information had been provided "it wasn't until I was [in my late teens] that I learned about Klinefelter's."

Georgina (a trans intersex woman with hypospadias) had been told by her mother when she was a child that she had been born with undescended testes. She recalled:

I saw the line on the scrotum and assumed this was a surgical scar. I was also aware that my urethra exited a fraction short of the end of the glands and that there appeared to be a short scar line there, too.

However, she found her mother's full diary references to her intersex status and childhood interventions only several years after her mother had passed away.

Tori (a woman with the intersex variation CAIS) was given no information about the various interventions she had undergone in relation to her intersex variation beginning in infancy. She found out that she had CAIS only in her thirties because she actively pursued the information, after having undergone removal of her gonads in infancy and hormone therapy in childhood. She suspected that information on her intersex variation had been secretly collected by medical practitioners. She bluntly recounted: "I stole my medical records from my endocrinologist's office. Yes, that's right, I *stole* them." The participants considered finding out about intersex variations through a document, rather than through being told, as a problematic and sometimes traumatizing method of discovery.

Immediate Families and Support

Participants in the study were asked about who in their lives knew about their variation. It was clear from their responses that the immediate families of most participants knew about their intersex variation. The participants' mothers (90%) or other primary guardians were overwhelmingly likely to know and were the family members most likely to have been told (Figure 2). Most fathers and other guardians were also

likely to know (79%), as were sisters (64%). Brothers were the least likely to know in the immediate family (57%); however, they were still more likely to have been told than not to have been told. Family members were more likely to know than were people at school (e.g., school staff and classmates), employers, or spiritual leaders. This underlines the importance of family relationships in the participants' lives and shows that within the immediate family at least, there was some discussion of the participant's intersex variation (if only at least to note its existence). However, close friends were particularly more likely to be told than some family members and were important overall, perhaps because of a lack of family acceptance.

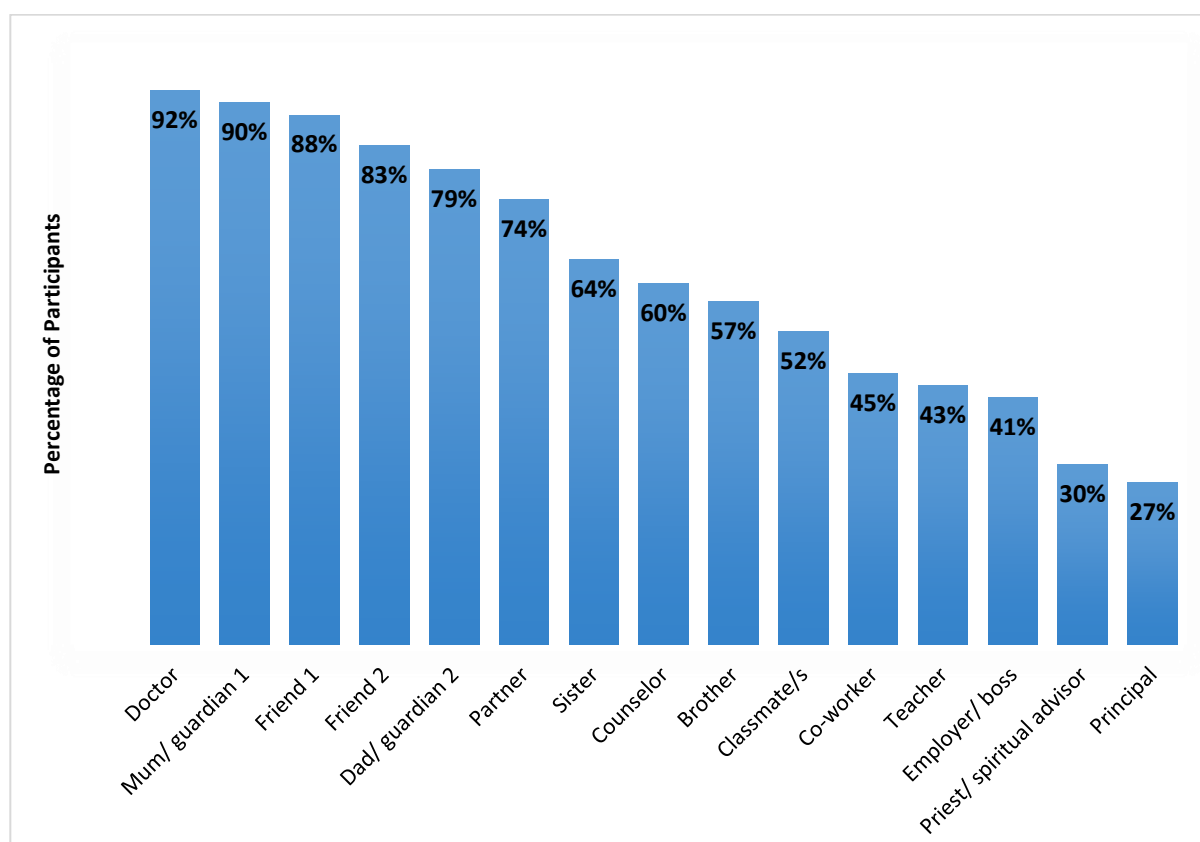


Figure 2. Percentage of participants with key people in their lives knowing about their intersex variations ($n=250$) (Jones, 2016).

Participants in the study were asked about how key people in their lives treated them regarding their intersex variations; participants'

responses showed that family members were not as supportive as their friends and romantic partners (Figure 2). However, approximately two-thirds of sisters were mostly supportive, and sisters were the most supportive family member overall. Just over half of mothers or primary guardians were also supportive. By contrast, most brothers were not supportive of participants regarding their intersex variations. Notably, fathers not only were unlikely to be supportive but also were the least supportive family member overall in participants' experience (just over a quarter were supportive). Both brothers and fathers had a neutral/mixed reaction to the participants' intersex variation, and in some cases their reaction was actively unsupportive.

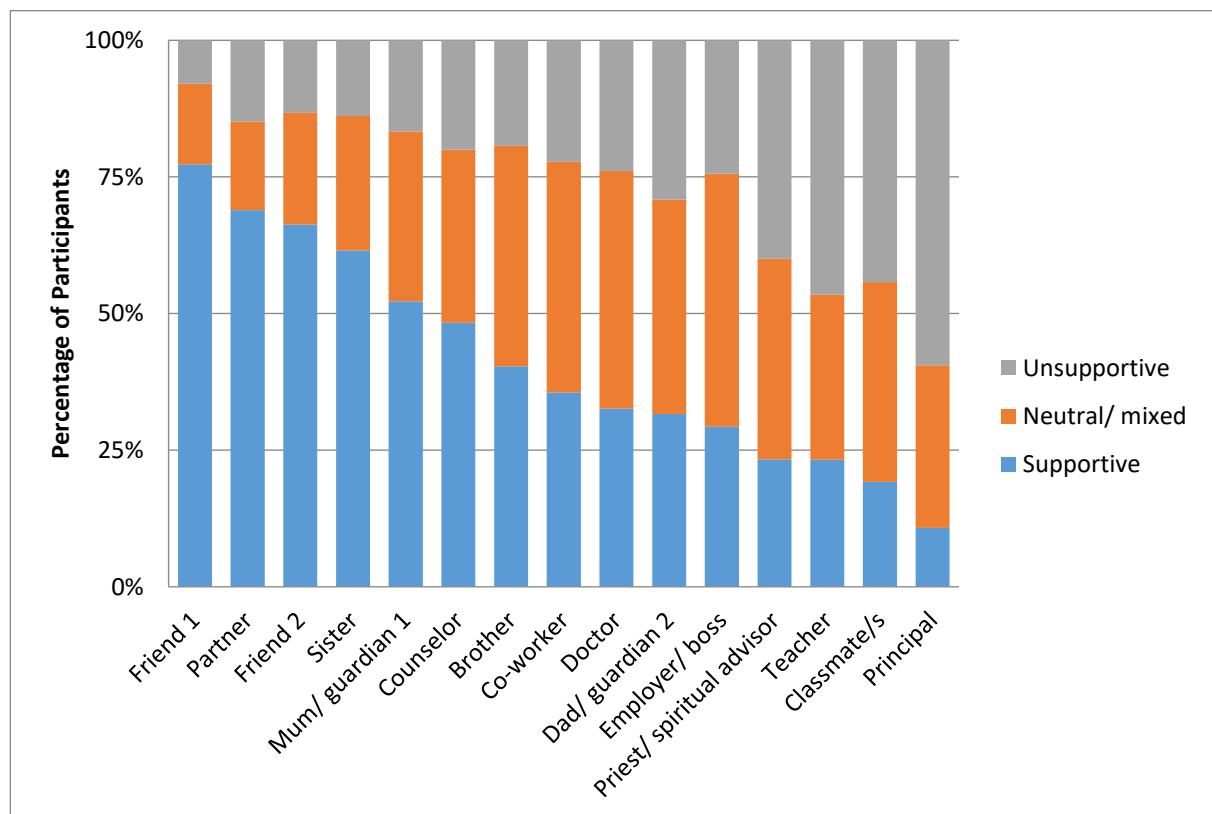


Figure 3. Reactions of key people in participants' lives to their intersex variations ($n=250$) (Jones, 2016).

Extended Families and Secrecy

Because of the largely congenital (although not necessarily hereditary) nature of intersex variations, the survey investigated the participants' knowledge of whether their variations or similar variations had occurred in others in their family backgrounds. Overall, the largest portion of participants (48%) knew that they did not have a relative with their variation or a similar one (Figure 4). In addition, 30% were unsure whether any of their relatives had their variations, and 22% knew that they did. The participants in this latter group usually had more than one relative with their variations – including siblings (10%), parents (6%), parents' siblings (6%), grandparents (2%), and/or another biological relative (8%). Intrafamily secrecy within the extended families of participants in the survey, regarding whether or not relatives had variations and how they experienced them if they did, was a strong theme that emerged in the qualitative data from the majority of participants (including both those who were unsure whether their relatives had their variations and those who knew that they did). A comment typical of most of those who were unsure was that an individual had “no idea” if any variations had been expressed in their families. There were also instances in which a participant who had selected “unsure” strongly suspected that a specific family member had their variation, but this could not be verified. Sometimes, a participant's parent or grandparent suspected that a much older relative might have had the participant's variation, but these family members had passed away long before medical methods of diagnosis were even possible.

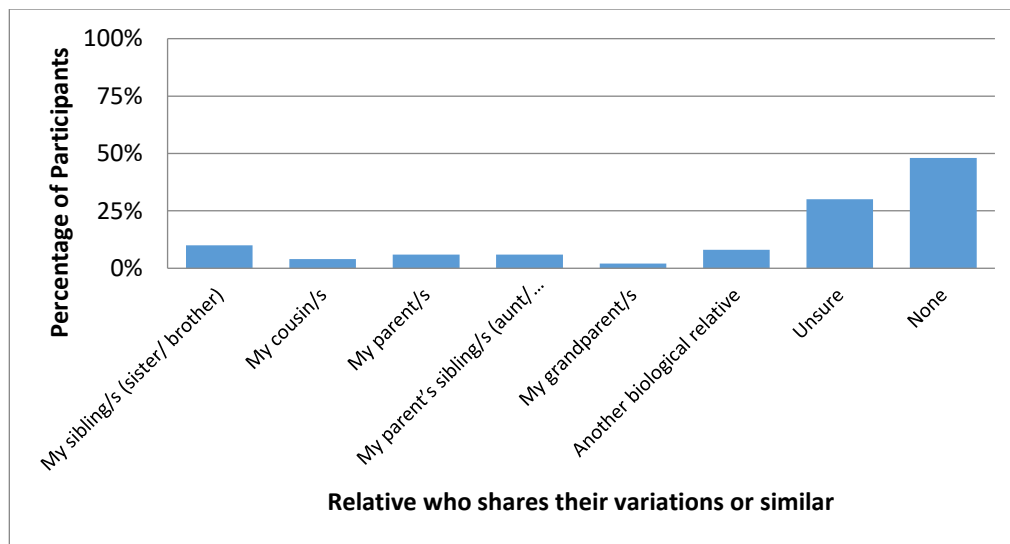


Figure 4. Participants with relatives who had the same or a similar variation ($n=250$).

Those who did know relatives with their variations often found out too late to discuss their experiences, or they struggled to share information given an established context of silence and the sometimes different features of their variations. For example, one participant with PCOS-related hyperandrogenism had excessive facial and bodily hair, infertility, and a variety of features that she learned a relative had also had before dying of related complications. Another reported an atmosphere of tension around her chromosomal variation, and she explained that it prevented her from finding out if others in her family background had same chromosomes because there was simply no way she could even ask them if they had her difference. There were participants with CAIS who had siblings, aunts, parents, and grandparents who either also had CAIS or carried the gene. One participant noted that although they assumed that this pattern continued back through the ancestral line, they could never know for sure because nearly all the people in their family and in their medical communities had been extremely secretive.

Parents and Gender Normativity

People with intersex variations were asked if they had received any counseling or training or experienced any pressure from their parents to act in a more feminine or more masculine manner. There were 43% who had received gender counseling or training from parents. The respondents provided 103 comments on these experiences; 44 focused on counseling/pressures to be feminine, 28 on counseling/pressures to be masculine, and the remainder on a range of other, smaller themes, most notably pressure to mature. The comments that focused on femininity often discussed clinical or familial pressure to become a “normal woman”; this was often conceptualized within the comments as pressure to wear dresses and long hair, remove any bodily or facial hair, play with girls, learn and perform domestic duties and hobbies, become physically capable of penetrative sex, and marry a man, for example. Comments on femininity were especially made by participants with androgen insensitivities, CAH, and PCOS-related hyperandrogenism.

The comments that focused on counseling/pressures around masculinity often discussed pressure to be strong, to go to the gym or build muscle, to be unemotional, to avoid clothing or behaviors seen as feminine, and to undergo HRT or “corrective” work on genitalia to fit

fathers' or other males' conceptualizations of maleness. Comments on masculinity were especially made by participants with XXY chromosomes and Klinefelter syndrome. Unfortunately, a few individuals reported being hit by a parent within the context of being shamed for perceived femininity or encouraged to increase their masculinity/strength. The comments that focused on counseling/pressures to be more mature discussed the pressure to "grow up," to engage in adolescent or adult interests and activities and forego "childish" play activities (watching cartoons or playing games), and to engage in or show interest in dating. There were several participants who discussed this pressure, which particularly came from parents and family members, including those with Kallman syndrome and TS, which are conditions that may affect puberty and development. Individuals were called late bloomers, late developers, short, childish, immature, scared, unlike the other boys/girls, and other labels. Participants felt keenly any parental disappointment in their inability to mature physically.

Parents and Early Intervention

Of the 272 people with intersex variations in the study, 60% (163 people) reported that they had undergone a medical treatment intervention related to their intersex variation (Table 2⁶). On average, they had undergone at least two interventions. The most commonly reported interventions were hormonal treatments, with 136 reports of the use of pills, injections, or creams. The second most commonly reported interventions were genital surgeries of varying kinds; 115 reports cumulatively included 52 of genital construction surgeries (vaginal/penal/labial or scrotal construction, shaping, or changes), 50 of gonad removal surgeries, and 13 of orchiopexies (surgeries to move one or two undescended testicles into the scrotum). There were also 40 reports of chest surgeries (including 21 reports of chest reconstruction/shaping and 19 reports of mastectomies), in addition to 28 reports of dilation treatments (insertion of objects into the vagina or frontal opening to expand it). There were also 43 reports of another type of surgery or treatment. Of the participants who indicated that they had undergone another type of intervention related to their intersex variation, most had undergone a unique type of treatment specific to their own medical practitioners' continuing overall treatment plans for their variations. For example, several participants with TS reported having different operations on various parts of their legs and joints to aid development and movement; these included Una (a female with the

⁶ Only interventions related to intersex variations are listed in Table 2. Interventions later chosen in relation to transgender status are not included because these are not the focus of this article.

intersex variation TS), whose surgeries were particularly focused on her knees “I had some surgery on my legs in my first few years to help with development problems.”

Table 2. Participants’ Reported Medical Treatment Interventions Related to Their Intersex Variations (*n*=272)

Interventions	Infancy (0-5 y)	Childhood (6-11 y)	Adolescence (12-17 y)	Adulthood (18-49 y)	Adulthood (50+ y)
Removal of gonad/s	14	10	15	12	2
Genital construction (vaginal/penal/labial or scrotal construction, shaping, or changes)	26	9	17	15	2
Mastectomy (breast removal/reduction)	1	1	5	14	1
Chest reconstruction/shaping	1	0	3	18	1
Hormonal treatments (pills/injections/creams)	4	16	66	90	14
Dilation treatments (insertion of objects into the vagina or frontal opening)	2	4	13	15	1
Orchiopexy/orchidopexy (surgery to move one or two undescended testicles into the scrotum)	5	2	4	2	0
Another surgery/treatment*	15	9	12	22	3

* Other surgeries and treatments included electrolysis/hair removal, removal of neck webbing, and a range of other interventions used for people with intersex variations.

Over half of all treatments (254 of the treatments reported, or 55% of all treatments) were delivered to participants when they were younger than 18 years of age. The youth of these participants at the time of treatment is especially important to consider, given that issues of consent for people younger than 18 years can be highly problematic when they are unsure of their position regarding a treatment or are more susceptible to

the influence of a range of adults (e.g., parents and medical practitioners). In addition, there was the possibility that any decision to undergo treatment related to one's sex presentation or gender identity might be considered differently during adulthood. It was particularly notable that there were 101 reports of genital surgeries in persons younger than 18 years (including 52 of genital construction, 39 of gonad removal, and 10 of orchiopexy), alongside 86 reports of people starting hormone treatment before age 18 (usually at or after the beginning of adolescence to coincide with the age at which puberty is frequently expected to begin).

Genital surgeries were therefore even more common than hormone therapies in people with intersex variations when they were younger than 18, and it is particularly poignant that there were 45 reports of genital surgeries conducted when the participants were in their infancy (0-5 years of age) – a life stage during which if consent is sought, it must be sought from parents/guardians rather than the individual affected. All surgeries of this nature have inherent risks (fatalities, infections, mistakes, etc.) that must be carefully weighed by the individuals considering them, so many participants whose surgery was chosen by their parents reported feelings of frustration that they had no say in the matter. The discussions of controversy surrounding matters of informed consent and bodily autonomy in the treatment of people with intersex variations encountered in the literature reviewed for this study (Creighton, Michala, Mushtaq, & Yaron, 2013; DPA Local Editorial, 2015; Ford, 2001) suggested that the frustrations the Australian participants sometimes reported in being forced into a particular sex or gender representation are still ongoing issues for families with children who have intersex variations.

Effects of Parents' Responses

To investigate participants' feelings about their intersex variations over time, the survey asked them how they felt about their intersex variations when they first found out they had them (Figure 5). The number of participants who had negative feelings was more than twice the number who had positive feelings about their variation when they first learned they had it. However, the survey also asked participants how they felt about their intersex variations at the time of the survey, and in contrast, most (56%) reported positive feelings about their intersex variation and its effects on their body at the time of the survey – well over twice as many as when they had first learned about their variation. Thus, the quantitative data show that although participants had mostly negative feelings about their variations initially, they had better feelings about their variations over time and ultimately appeared to have mostly positive feelings about them.

The qualitative data also supported this finding. For example, Selma (an intersex woman with 47,XXY syndrome) stated, “I was forced on testosterone at 15 years. They tried to correct my body and my behavior. Now I’m embracing it.”

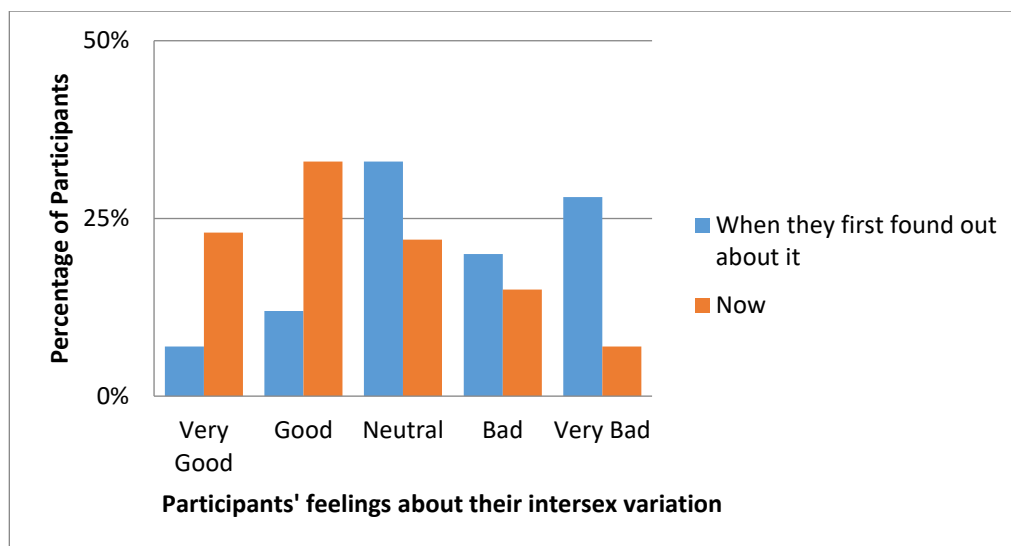


Figure 5. Comparison of how participants felt about their intersex variations when they first learned of them and how they feel about them now ($n=250$).

It was important to explore why participants initially felt so much worse about their intersex variations than they did later, and the participants' comments shed some light on this. Many people who initially felt bad about their intersex variations found out about them in traumatizing circumstances, such as immediately before, during, or even a long time after they had undergone tests or treatments to “correct” their bodies in some way (including quite serious surgeries and HRT). This could create a context in which participants felt as if their bodily autonomy or life choices had been taken away from them by a combination of their own family and medical institutions. They felt as if their body needed to be “fixed” and/or was not classed within the broad spectrum of healthy (if not necessarily common) bodies, or that people could touch and judge their bodies with little to no permission. For example, Eunice (a woman with the intersex variation PAIS) found out during her primary school years that she had undescended testes. “I found out about it in the context of ‘so you are

having an operation,” she explained, “so I was extremely scared. Very frightened of being cut open.” She was given no alternative choices by her family about how she could react to her body and was not told that she had the right to avoid the surgery or subsequent interventions, such as the hormone therapies and genital reconstruction surgeries she had experienced. She said she was told “no detail – just that I had testicles like my brother and they were going to be taken out because unlike my brother ... I was a girl.” She now feels neutral about her variation after feeling bitter about what had been done to her, yet:

On the other hand, I feel much more open and accepting about being intersex and having AIS, I see that the body would naturally have coped with this if I had not been interfered with by the medical institution.

Louise (a woman with CAIS, 38 years old) had been told a little about her variation after she had been placed on hormonal therapies in childhood and then asked to use dilation therapies to expand her vagina in her teens. She recalled her parents’ distress but did not understand the “reasons for the adults around me to be so upset.” Her experience was defined by the negative emotional setting established in conversations with family about her variation, and she mirrored their responses. Particularly, she learned of their reservations about the possibilities for her life and their general silence on the topic as a strategy in her own life: “My parents’ discouragement of relationships in favour of a career made me feel that I would never be wanted ... and that my inability to have children was reason for intense grief.”

There was a strong message across the qualitative data that participants felt themselves to be affected by any negative emotions and attitudes about their variations conveyed by the people (mainly parents and doctors) who first told them about the variations. This effect occurred particularly when they were younger than 18 years of age and before they had access to alternate sources of messaging regarding their variation, such as support groups. In addition, many participants who initially had negative feelings about their variations were given little to no information about the experience of having variations, and there was no real affirmation from parents or family about having variations that would help them to frame the variations positively in their minds. For example, Andy (an intersex man with Jacob/XYY syndrome) felt “very bad” when he was first told about his variation as a teenager because he said he did not know exactly “what” he was. He was subjected to negative treatment from

parents about his gender expression and pressure to be “manly,” and he became suicidal without any real supportive assistance around his variation from medical bodies, faith groups, or his home. In later years, it significantly helped Andy to look up support groups for people with intersex variations online. He reflected that after this exposure, he now feels “very good” about his variation and its effects on his body and has more information; “When you know what you are, you can learn to live with it.” Similarly, Chris (an intersex individual with 47,XXY syndrome) felt “very bad” about the initial experience of receiving minimal information about this diagnosis as a teen but had more recently received full access to medical records and information about chromosomes from a more supportive doctor and now felt “very good” about the variation. These findings refute the presumption that intersex status is something people will necessarily feel *intrinsically* bad about *in itself*, as seen in historical psychological and medical theorization (Jones and Lasser, 2015). Instead, the data suggest that familial constructions of intersex status certainly have an important role to play, alongside medical and social constructions; they may not only influence a child’s view immediately upon discovery of the variation but also later become a source of tension or disagreement after exposure to alternative views.

Views on Parenting Debates

Participants were asked about their views on children with intersex variations and how parents might consider their roles in relation to such children (Table 3). Although there was some variance, the participants’ views were overall against children with intersex variations being treated in ways that did not privilege their social equality and bodily autonomy. For example, 81% of participants disagreed (or strongly disagreed) with the proposition that “people should select against having intersex offspring (e.g., by using in vitro fertilization selection techniques).” Moreover, the participants’ views suggested a protective role for parents around interventions aimed at aesthetically “correcting” their children’s variations. Of the participants, 75% disagreed with the proposition that “children should have genitals that precisely match the sex they are reared as”; 88% disagreed with the proposition that “genitals (e.g., clitoris or penis) that do not fit a size ‘norm’ should be surgically altered in size”; and 92% disagreed with doctors engaging in surgical interventions without knowing the long-term outcomes.

When parents are placed in the position of potentially being the persons to consent (or withhold consent) to such surgical interventions, most participants would not want them to consent to medical interventions

automatically (if the opportunity to consent were indeed offered). In addition, 92% of participants disagreed with the proposition that “health providers should be able to apply interventions (e.g., surgeries, sterilization, hormonal treatments) to their sex characteristics without their informed consent” – a practice that this study has shown can happen for children with intersex variations. Finally, just less than one-tenth of the group (9%) agreed that their parents had been given adequate choices and information about their child’s intersex variation when it was first diagnosed. It is therefore important for the parents of a child with an intersex variation to understand that during the initial period around the diagnosis, they may not have all the information they need to understand either the child’s diagnosis or the health care and treatments the child may one day wish for. Participants largely believed their parents had not had adequate information to offer consent to treatments on their child’s behalf – suggesting a need for greater caution regarding issues of consent.

Table 3. Participants’ Reported Views on Parenting Debate Topics Related to Their Intersex Variation ($n=170$)

Parenting Debate Topic	Strongly Agree	Agree	Neutral/ Unsure	Disagree	Strongly Disagree
Children should have genitals that precisely match the sex they have been reared as.	5	9	28	34	94
Genitals that do not fit a size “norm” should be surgically altered in size.	4	3	14	25	124
Doctors should perform surgical interventions on intersex kids without knowing the long-term outcomes.	3	1	9	21	136

People should select against having intersex offspring (e.g., by using in vitro fertilization selection techniques).	3	5	25	24	113
Health providers should be able to apply interventions to my sex characteristics without my informed consent.	4	1	9	15	141
Adequate choices and information were given to my parents about my congenital sex variation when it was first diagnosed.	8	8	38	24	92

Discussion of Results

Overall, the data show that there are many complications for people with intersex variations and their families, especially when intersex variations are viewed by the family members (particularly parents) as problematic. Families could delay discussing intersex variations with their children if they saw the variations as shameful, and although most immediate family members (parents/guardians and siblings) ultimately did know about and discuss the variations, their support was viewed by people with variations as mixed. Male family members (fathers and brothers, particularly) may offer neutral or mixed responses to intersex variations, or in some cases even be actively unsupportive. Members of extended families contributed to secrecy, with grandparents and aunts/uncles, for example, sometimes suspected of withholding information about the hereditary nature of

intersex variations in the family line or simply not sharing their own experiences. Some parents pushed gender normativity onto their children with intersex variations, encouraging them to be more masculine or feminine or pushing for developmental stages that might be out of reach for individuals whose puberty was delayed or experienced differently. Some parents also supported early interventions (surgeries or hormonal treatments) without allowing any autonomous decision making on the part of their children around their own bodies and treatment needs – sometimes with negative outcomes for these individuals as they matured or with family tensions over time. Indeed, the way both parents and families generally considered intersex variations could have an effect on how people with intersex variations felt about their own variations and could have very concrete effects on their bodies and treatments over time.

Despite these issues, the data showed clear pathways for families to care better for members with intersex variations in the future. Specifically, people with intersex variations want parents and guardians to take a more protective role overall in avoiding early medical interventions, a lack of informed consent, and being treated in ways that do not privilege their children's bodily autonomy. They also emphasized their experience of a lack of information for both parents and themselves, and therefore the need for families in general to actively seek to become better informed about intersex variations before making any decisions about interventions and to overcome issues of secrecy and misinformation. They want members of immediate and extended families to contribute their own experiences and support more openly.

Conclusion

The data confirmed the hypothesis that family relationships are strained by intersex variations when these variations are viewed as problematic disorders. The data also showed that participants wanted their families to embrace their natural (intersex) bodies more strongly rather than seek early “corrective” measures, to protect them from early medical intervention, and to engage in more information sharing. To facilitate fulfillment of these wishes, social and medical services will need to develop better familial group support and familial group counseling around intersex variations, and more open and accessible methods of information dissemination about intersex variations to individuals and their family members. This will be essential to combat past patterns of institutionalized shaming and the coercive treatment of people with intersex variations, and their negative effects on family dynamics. Health and mental health practitioners will need intersex-affirming information and family therapy

tools that they can use in talking with family members about the importance of open communication and acceptance with their intersex children and other family members. Policymakers and advocates should consider this research in working together toward fulfilling requirements for information dissemination to families and individuals with intersex variations broadly, and toward ensuring consent for interventions.

Further research needs to be conducted on the best ways of supporting medical institutions and systems in emphasizing the rights of intersex young people and better informing their families about their rights and needs in family and medical contexts. Specifically, action research could take place within health departments, hospitals, and clinics around processes supporting information dissemination to families, improved family counseling therapy models that emphasize the bodily autonomy of intersex youth, and improved medical training to make people with intersex variations the primary determining parties in their own medical care when possible (with the support of family members and guardians). Key strengths of the study are that it involved people with intersex variations in its development and emphasized intersex voices. However, future studies should also incorporate a critical lens focusing on clinical practice and research that emphasizes intersex patient rights and empowerment and encourages the inclusion of intersex community leaders and representatives in service and research development processes (e.g., seen in Davis, 2015b, and in Jones, 2016), in ways fitting the participatory goals of the respondents in this research. Limitations of the study are its lack of inclusion of psychomedical and family support organization representatives and participants, whose perspectives and aid should be considered crucial in the next phase of research on improving intersex health care and family support. A more holistic, cross-disciplinary approach to research will be required to ensure that future action-focused studies have lasting effects to strengthen people with intersex variations and their families.

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